



Connecting Parents and Families

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Parenting a Child with Special Health Care Needs

Being a parent is a joyful, rewarding experience. At times, it can also be the most difficult and stressful job there is.

You probably have a lot to do every day to meet your child's needs.

When your child has special health care needs, your daily 'to do' list is even longer. In addition to taking care of laundry, meals, and giving homework help, you might also need to:

- Call your child's primary care provider (PCP) for a referral to a specialist
- Pick up medications at the pharmacy
- Give your child medications
- Take your child to medical appointments
- Call the insurance company to get pre-approval for a hospital admission
- Schedule an assessment with Early Intervention
- Meet with the school nurse to review your child's health plan
- Get your child's medical equipment fixed

Life is even more complex if you have other children.

Taking care of yourself is very important. When you are busy taking care of everyone else's needs, it is easy to forget to take care of yourself. This chapter provides information for you about:

- Taking care of yourself
- Emotional Support
- Getting connected with other families
- Tips on advocating for your child and family

This information is not meant to make your 'to do' list longer. It's meant to help support you in caring for yourself and your child. Look over the suggestions in this chapter. Pick one or two activities that sound appealing. Once you've tried one, it may be easier to try others.

Taking Care of Yourself

It is hard to care for others when you're overtired, stressed-out, and rundown. Try to take some time for yourself every day. Start by taking 5 or 10 minutes to do an enjoyable and relaxing activity. Here are some suggestions from other parents:

- Take a walk, stretch, or enjoy some other type of exercise
- Read a book or magazine - just for fun
- Talk to a friend
- Sit down and have a cup of tea
- Watch a sports event on television
- Go to a movie
- Meditate, or at least take a few deep breaths
- Take a nap
- Take a bubble bath
- Go to sleep a few minutes earlier each night for a week

Asking for Help

Raising a child with special needs can be tiring and overwhelming. There may be times when you feel angry, frustrated, or when you blame yourself. Sometimes you may feel sad or anxious. ***It is normal to have any or all of these feelings at times.***

Remember that you need care too. Talk to someone you trust about your feelings. Emotional support can come from friends, family, other parents, support groups, and health care providers. You are doing a very important job. You don't need to do it alone. There are many kinds of help and support. ***It is okay to ask for help.***

Getting Connected with Other Parents

The experience of raising a child with special needs may not be what you expected. Your hopes and dreams for your child may have taken a different path.

You are not alone, even though at times you may feel that way. There are large networks of parents raising children with special needs. They use different ways to share information and support each other—talking to each other on the phone, writing email, and going to parent groups are just a few ways.

One good place to start is by contacting **Massachusetts Family TIES (Together In Enhancing Support)**. Family TIES is a statewide information, referral, and parent support network for families of children with disabilities or chronic illnesses.

Family TIES offers:

- **Parent-to-Parent Matches** – A program that matches a parent to another parent whose child has a similar diagnosis.
- **Support Group Information** – Listings and contact information for general and disability-specific support group meetings in your local area.
- **Information and Resources** – A Parent Coordinator can provide up-to-date information, services, and resources. Many of these are also listed in the ***Family TIES Resource Directory***.

Contact Family TIES at 800-905-TIES (8437), 617-624-5992 (TTY), or visit www.massfamilyties.org. A Parent Coordinator can help connect you to other parents and supports.

There are many other places to find support and resources. Look on the next page to find a list of resources for parents in Massachusetts. Also, check the ***Family TIES Resource Directory***.

Tip:

Check to see if your child's hospital has a family center, parent group, or parent advisory committee to join and meet other parents.

Resources for Parents and Families

For parent resources and support:

Massachusetts Family TIES (Together In Enhancing Support) is a statewide information, referral, and parent support network for families of children with disabilities or chronic illness. Check the ***Family TIES Resource Directory*** for resources. Contact **Massachusetts Family TIES** at 800-905-TIES (8437), 617-624-5992 (TTY), or visit www.massfamilyties.org.

For services for your young child, birth to age 3:

Early Intervention (EI) is a program for infants and toddlers who currently have, or are at risk of having, a developmental delay. Contact **Massachusetts Family TIES** at 800-905-TIES (8437), 617-624-5992 (TTY), or visit www.massfamilyties.org to find an EI program near you.

For public health supports and services:

Massachusetts Department of Public Health (DPH) offers programs and services to children with special health care needs and their families. Call the **DPH Community Support Line** at 800-882-1435 (in MA only), 617-624-5070, 617-624-5992 (TTY), or visit www.mass.gov/dph/fch/directions.

For information about developmental disabilities and mental retardation:

Massachusetts Department of Mental Retardation (DMR) offers support services for children with mental retardation and their families. Contact **DMR** at 888-DMR-4435 (888-367-4435), 617-624-7783 (TTY), or visit www.mass.gov/dmr.

Arc of Massachusetts. The mission of the Arc is to enhance the lives of individuals with cognitive and developmental disabilities and their families. Arc helps to improve supports and services in the community. See the **Arcs** section of the ***Family TIES Resource Directory*** to find the contact information of your local Arc office. Also, contact the **Arc of Massachusetts** at 781-891-6270, 781-891-6271 (TTY), or visit www.arcmass.org.

For mental health supports and services:

Massachusetts Department of Mental Health (DMH) offers community-based services to children and adolescents with mental health diagnoses. Contact **DMH** at 617-626-8000, 617-727-9842 (TTY), or visit www.mass.gov/dmh.

PAL, Parent Professional Advocacy League, is a statewide network of parents and professionals supporting children with mental, emotional, and behavioral needs. Contact **PAL** at 866-815-8122 or visit www.ppal.net.

For information about special education services:

Massachusetts Department of Education (DOE) provides special education services and accommodations to children with special health care needs. Contact the special education department at your child's school, **DOE** at 781-338-3300, or visit www.doe.mass.edu/sped.

Federation for Children with Special Needs provides information, support, and assistance to families of children with special needs and professionals. The Federation also offers individual support and workshops about special education. Contact the **Federation** at 800-331-0688 or visit www.fcsn.org.

For resources in MA and around the United States:

National Dissemination Center for Children with Disabilities (NICHCY) provides disability-specific information and state-by-state listings of resources. Contact **NICHCY** at 800-695-0285, 202-884-8200 (TTY), or visit www.nichcy.org.

National Organization for Rare Disorders (NORD) provides detailed medical information, support group listings, and other resources for specific disorders. Contact **NORD** at 800-999-6673, 203-797-9590 (TTY), or visit www.rarediseases.org.

To receive a magazine about parenting a child with special needs:

Exceptional Parent Magazine provides information and support for members of the special needs community. Call 877-372-7368 or visit www.eparent.com.

For browsing the Internet:

Family Village is a website with information, resources, and communication opportunities for people with disabilities, families, and providers. Family Village includes informational resources on specific diagnoses, communication connections, adaptive products and technology, adaptive recreational activities, education, worship, health issues, disability-related media and literature, and much more. Visit www.familyvillage.wisc.edu.

For information about:

- Connecting with parents and professionals throughout Massachusetts
- Partnership opportunities for parents and professionals
- Improving systems of care for children with special health needs

Massachusetts Family Voices is a grassroots network of families and friends speaking on behalf of children with special health care needs. Mass Family Voices offers advocacy, support, education, and information. Mass Family Voices hosts a listserv where families and professionals share information, exchange resources, and post questions. Contact **Mass Family Voices** at 800-331-0688 x 210, 617-624-5992 (TTY), visit www.massfamilyvoices.org, or join the listserv by sending email to massfv@fcsn.org.



Recreation and Support for Your Child

Making friends and participating in recreational activities is important for your child – just as it is for all children. You may have to work a little harder to make sure your child has these opportunities. Here are some suggestions that may help your child with making friends:

- **Meet other families in your neighborhood and at your child's school.** Attend school events such as open houses, parent meetings, and other school functions.
- **Invite children and their families to play and do things together.** Ask them to come to your home or suggest an activity, like going to the library or a park. While the children play, you can enjoy a few minutes to talk with other parents.
- **Talk to your child about what it means to be a friend.** Encourage your child to introduce him or herself, smile, and shake hands.
- **Work with your child's teachers to help your child develop friendships in school.**
- **Participate in community recreation programs.** Work with staff at the program to develop and carry out any accommodations your child might need.

Your child may want to connect with another child or adult who has a similar disability. Many **Arcs** host support groups and activities for children and youth with special needs.

Check the **Arcs, Recreation/Arts, Camps, and Community Support and Parent Networks** sections of the **Family TIES Resource Directory** to find more information on recreational programs for your child.

Some Internet sites host on-line communities where children with special needs can talk about their experiences, share ideas, and support each other. Take a look at:

- **Starbright World**, an on-line community of over 30,000 kids with chronic illnesses. Visit www.starbright.org.
- **Club Bravekids**, a website for kids growing up with chronic illness. Visit www.bravekids.org.
- **Partners for Youth with Disabilities** has an on-line mentoring program, as well as other individual and group mentoring programs. Visit www.pyd.org.

Connecting Brothers and Sisters – Sibling Supports

Being a brother or sister of a child with special needs can be tough.

Siblings sometimes feel:

- Guilt that they are 'normal'
- Embarrassment about their sibling
- Fear that they will develop the same illness or disability
- Anger about the attention their sibling receives
- Loneliness

Brothers and sisters may also need support to help them deal with these feelings. Give them age-appropriate information about their sibling's disability or condition. This can help siblings deal with feelings about their brother or sister's special needs and answer questions they might have.

Siblings also need a chance to talk to other children who have some of the same feelings and experiences. The **Sibling Support Project** at **Arc** recognizes the unique needs of brothers and sisters. They offer workshops, provide educational materials, and maintain a database of other sibling supports.

Your child may want to connect with other siblings of children with special needs on the Internet. The Sibling Support Project hosts two listservs. Parents are welcome to listen in on both lists.

- **Sibnet** is a listserv for adult brothers and sisters of people with special needs.
- **SibKids** is for young brothers and sisters.

Visit the **Sibling Support Project** at www.thearc.org/siblingsupport.

For other information about sibling support groups in your area, contact Family TIES, your local Arc, or your child's primary care provider (PCP).

Speaking Up for Your Child

All parents need to speak up, or advocate, for their children to make sure they are treated fairly. Just as you speak up for your child on the playground or in school, you also need to speak up for your child's special needs. This means speaking up for your child's needs with health care providers, educational professionals, and health plans.



Tips on Speaking Up for Your Child

- Remember that you are the expert about your child. Be prepared to provide information about your child's special needs, strengths and weaknesses, and accommodations that have worked.
- "Knowledge is power," says one parent of a child with special needs. Get information from more than one place and more than one person. Use all the information you have to speak up for your child's needs.
- Go to meetings, workshops and conferences. These are great places to learn ways to speak up for your child. Also, you can talk to other parents and learn about what works for them.

Communication

You probably have a lot to say about your child's needs. It takes practice to learn how to communicate clearly and well. The better you communicate, the more helpful and respectful your relationships will be with providers and professionals. Use these tips for meetings, phone conversations, and writing letters about your child.

Communication Tips

- At meetings, smile, introduce yourself, and shake hands.
- Bring a list of issues and concerns to discuss at the meeting, and hand it out.
- Bring a friend – two sets of ears are better than one.
- Listen carefully to what others say, and take notes.
- If you don't understand something, ask for an explanation. Don't be afraid to say, "I don't understand."
- Emphasize your child's needs instead of your own. For example, when you want a particular accommodation or modification for your child, use the phrase, "My child needs..." instead of "I want..."
- Talk about your child's strengths. This way, people can focus on helping your child succeed, not just get by.
- Show a photograph of your child. Sometimes pictures are worth more than words.
- Be positive. When you are asking for a service or an accommodation, try to keep a positive attitude.
- If you don't agree with decisions being made, speak up. Use expressions like, "I disagree." If you get angry or upset, try to stay focused on the discussion – not the feelings. Talk about the feelings later with people that you trust.
- Try to end meetings on a positive note. If you can't come to an agreement about a particular issue, try to 'agree to disagree' about that topic. Set another meeting time, or agree to continue the discussion on the telephone or via e-mail.
- Remember to thank people. Meeting your child's special needs can be hard work for everyone.